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Nate Checketts
Deputy Director
Utah Department of Health
PO Box 143106
Salt Lake City, UT 84114

RE: GHLF Patient Group Opposes Utah 1115 Demonstration Waiver Application, Per Capita Cap

Dear Director Checketts,

The Global Healthy Living Foundation (GHLF) writes to you on behalf of the newly proposed amendments to the Section 1115 Primary Care Network Demonstration Waiver, Per Capita Gap.

By way of background, GHLF is a 20-year-old non-profit patient organization reaching millions of chronically ill patients and their caregivers across the country through social media, community events and online support and education. GHLF works to improve the quality of life for patients living with chronic disease by making sure their voices are heard and advocating for improved access to care at the local level. Our patients suffer from chronic conditions including arthritis, psoriasis, gastrointestinal disease, cardiovascular disease and migraine. As a result of their chronic illness and higher healthcare needs, these patients are exceptionally dependent on attaining and maintaining health insurance access. Several studies, including the Oregon Health Insurance experiment, suggests that any form of healthcare coverage is better than no healthcare coverage at all. One of the biggest shifts it provides, which is particularly applicable to our patient population, is the significant decrease in financial strain. Therefore, it is on behalf of these patients that we write to express our ongoing opposition to Utah's 1115 Demonstration Waiver Application.

Medicaid has grown and expanded to cover 70 million people, or 1 in 5 people in the county. As stated above, individuals significantly benefit from health insurance coverage. GHLF represents many patients covered by Medicaid and we are committed to ensuring that Medicaid provides, and continues to provide, individuals with health insurance coverage that is adequate, affordable and accessible. In November of 2018, Utah voters voted to improve access to healthcare by expanding Medicaid coverage to individuals with incomes below 138 percent of the federal poverty level (\$28,577 for a family of three). This decision would have allowed coverage to expand to 150,000 low-income individuals in the state. However, through a recently approved waiver by the Centers for Medicare and Medicaid Services (CMS) and Utah's current waiver application, Utah is now moving forward with a plan that would produce the opposite effect of what was democratically decided. This will reduce the number of individuals able to access comprehensive, affordable health insurance coverage, adding add new barriers to the already limited Medicaid program. GHLF strongly opposes this reversal and offers the following comments on Utah's waiver.

Per Capita Cap

GHLF opposes Utah's proposed amendments to change the financing structure of its state Medicaid program to a per capita cap model. This cap is designed to limit the level of funding provided by the federal government to a state for its Medicaid program. This forces states to either fill the funding gap with their own state funds or cut the program by reducing the number of people they cover and the provided benefits. These cuts are inequitable to Utah's of chronically ill patients represented by GHLF as well as those who represent themselves and voted to expand Medicaid. These cuts are detrimental to their wellbeing and livelihood by not only reinstating a significant financial strain, but also dramatically limiting their access to life-saving treatments.

Utah's application does not speak to how it fill the funding gap caused by the state's new per capita cap. GHLF fears the state will cut coverage to certain treatment options and therapies or impose additional barriers to important services. Again, this is a dramatically inequitable shift in healthcare access for patients who are highly reliant on adequate healthcare coverage. For example, with patients who suffer from one or more chronic illness and/or autoimmune disease, their access to and coverage of prescription medication is consequential to their health and wellbeing. Without access to their prescription medications and therapies, their progress in their illness treatment will be reversed, leaving many in a crippled, debilitating, or even life-threatening state.

GHLF additionally fears Utah's choice to cut payments to providers is an attempt to keep spending under the new per capita cap. Due to the current stigma associated with Medicaid and the lower reimbursement rates in comparison with private insurance and Medicare, Medicaid and CHIP beneficiaries already experience longer wait times and have immense difficulty in finding a provider who will treat them.

The negative impact of the per capita cap on chronically ill patients and those who suffer from autoimmune disease would be exacerbated by the enrollment limits already approved in the state's previous waivers and the state's request to continue in this application. Utah would provide itself with the ability to close enrollment for the adult expansion eligibility group "when projected costs exceed annual state appropriations." Even though Utah is not expecting this policy to impact enrollment, the additional financial pressure caused by the per capita caps suggests the impact on enrollment is definitely a concern, as a large number of individuals could be off coverage.

Utah's application requests that CMS allow the state to make changes to its per capita cap with a few conditions. The inclusion of these special conditions supports the idea that a per capita cap financing structure does not protect either the state or its Medicaid enrollees from financial risk in the case of an economic downturn or other unexpected event. The exemptions to the request are not clearly defined and not sufficient to protect the state if healthcare costs grow above the per capita cap. For example, there are many ground-breaking treatments in development for our chronically ill patient population. If an expensive, but highly effective treatment became available for these patients, Utah's spending could rise above the cap; thus, putting the state's budget at risk and incentivizing the imposition of additional barriers for that treatment.

Finally, if Utah was actually concerned about the fiscal sustainability of Medicaid program, the state could submit a state plan amendment that matched what Utah residents democratically voted for: to fully expand Medicaid to 138 percent of the federal poverty level and receive a 90 percent reimbursement from the federal government for all expenses for the adult expansion population without any per capita cap. This policy would not only benefit the state financially, but would also expand access to care to more low-income individuals who need coverage. This is the core purpose of the Medicaid program.

Program Lockout

Utah's waiver additionally includes a new six-month lock-out for individuals in the adult expansion population that the state has convicted of committing an intentional program violation (IPV). We believe this provision to be unnecessary, as the state currently has the ability to take individuals to court for possible fraud and ensure ongoing protection of the fiscal sustainability of the program. GHLF additionally opposes this specific proposal.

The addition of this provision would increase the administrative burden on both the patients as well as the state Medicaid program and, as the state of Utah acknowledges, result in coverage losses. For example, under this new policy, an IPV would include simple acts such as failing to report a required change within ten days. GHLF fears that patients could be confused over what they are required to report or get overwhelmed in trying to provide the required information, resulting in patients losing coverage. Dealing with the administrative responsibilities and obligations in order to keep coverage should not take away from patients' or caregivers' attempts to maintaining their or their family's health.



Presumptive Eligibility

Utah's waiver would prevent hospitals from making presumptive eligibility determinations for individuals in the adult expansion population and continue to prevent hospitals from making these determinations for the targeted adult population. Presumptive eligibility allows hospitals to provide individuals with Medicaid coverage temporarily, if the individual is likely to qualify for Medicaid. This is an extremely important entry incentive for patients who are not yet enrolled. This allows patients to not only gain an understanding that they are eligible for Medicaid, it additionally helps protect patients from large medical bills and incentivizes seeking treatment before the illness or infection escalates to more expensive or debilitating levels. For this reason, GHLF opposes this request.

Previously Approved Provisions

Utah's application also requests an extension on certain features that have already been approved by the CMS in the state's previous waiver. GHLF continues to hold serious concerns about the impact these policies pose on Utah's chronically ill patients we represent.

Work Requirements

Under the application, individuals in the adult expansion population would be required to complete job search and training requirements prior to receiving Medicaid coverage, unless they either demonstrate they work at least 30 hours per week or meet other exemption criteria. One major consequence of this proposal will be the inevitable increase in the administrative burden on individuals in the Medicaid program. Increasing administrative requirements will likely cause a decrease in the number of individuals who apply for or maintain their Medicaid coverage, regardless of whether they are exempt or not. In other words, this provision enforces an additional constraint and barrier to accessing health insurance coverage for a population that already experiences increasing inaccessibility burdens. For example, Arkansas implemented a similar work requirement in June, 2018, in which enrollees were required to report their total work hours or provide proof of exemption. During the first 6 months of implementation, the state of Arkansas terminated coverage for over 18,000 individuals and placed them on a lockout until January of 2019.¹ In 2003, Washington state altered its work requirement by changing the renewal process from every 12 months to every 6 months and enforced new documentation requirements. By the end of 2004, about 35,000 fewer children were enrolled in the program. These two anecdotes present precedent of how enforcing a work requirement can severely obstruct individual access to Medicaid coverage.

Failing to fulfill these burdensome administrative requirements could have serious negative implications for our patient population living with serious, acute and chronic diseases. If Utah finds that an individual has failed to comply with the new requirements after three months, their essential health insurance coverage can be taken away. For individuals who are in the midst of treating their life-threatening disease, they rely on their ability to regularly access their healthcare providers and maintain their prescription medication routine in order to manage their chronic conditions and symptoms. With this gap in care, they lose this control and illness management capacity.

GHLF is also concerned that the current exemptions criteria for the work requirement provision may not capture all individuals with, or are at risk for, serious and chronic health conditions that may prevent them from working. Moreover, enrollees who are exempt are still required to provide approved documentation of their medical condition from a medical professional or other data source. This creates a potential for additional administrative error that may jeopardize individual coverage. No exemption criteria can avoid this problem and the serious health risk it poses to the patients we represent.

¹ Robin Rudowitz, MaryBeth Musumeci, and Cornelia Hall, "A Look at November State Data for Medicaid Work Requirements in Arkansas," Kaiser Family Foundation, December 18, 2018. Accessed at: <https://www.kff.org/medicaid/issue-brief/a-look-at-november-state-data-for-medicaid-work-requirements-in-arkansas/>; Arkansas Department of Health and Human Services, Arkansas Works Program, December 2018. Available at: http://d31zhk6di2h5.cloudfront.net/20190115/88/f6/04/2d/3480592f7fb6c891d9bacb6/011519_AWReport.pdf



Administering these requirements will become a financial burden for the state of Utah. States, including Kentucky, Tennessee, and Virginia, have estimated that the resources required for the administrative systems needed to track and verify exemptions and work activities will cost tens of millions of dollars.² This would be a misuse of federal resources, as it would take away from Medicaid's true objective of providing health coverage to those without access to care, and lead to compromising the financial health of Utah's Medicaid program.

These requirements do not facilitate or foster the purpose of the Medicaid program. The program is structured to help low-income individuals improve their physical and mental health without needlessly compromising their access to care. Most individuals who are enrolled in Medicaid and who are able to work already do³. A study published in JAMA Internal Medicine analyzed the employment status and demographic characteristics of Michigan Medicaid enrollees. The study found that about a quarter, only 27.6 percent, of enrollees were unemployed. Of this 27.6 percent, two thirds reported having a chronic physical condition and a quarter reported having either a mental or physical condition that interfered with their ability to work⁴. A separate report which analyzed the impact of Medicaid expansion in Ohio, found that 83.5 percent of enrollees felt that their enrollment in Medicaid made it easier to work and 60 percent reported that it made it easier to look for work. That report also found that many enrollees were able to access and receive treatment for previously untreated health conditions; in turn, making it easier to find work⁵. Terminating individuals' Medicaid coverage for non-compliance with these work requirements will have an opposite effect by inhibiting their ability to search for and obtain employment opportunities. GHLF opposes this policy.

Enrollment Limits

As previously mentioned, this application includes a proposition to continue the previously approved enrollment limits for the adult expansion and target adult populations. GHLF opposes these enrollment limits.

Most importantly, these enrollment limits will inevitably harm patients. This policy will inhibit patient access to preventive services, necessary regular visits with health care providers, daily medications that patients require to manage and maintain their chronic conditions, and remove or limit access to life-saving treatment for other serious illnesses. Under this policy, if a patient is diagnosed with a life-threatening disease that requires immediate treatment but are denied coverage, they are forced into choosing between delaying care or costly medical bills. Seeking medical care at a later date, in comparison with getting help when it was initially required, presents the strong probability of even more extensive and expensive medical bills. This denial of coverage is not consistent with the statutory objectives and purpose of the Medicaid program.

Individuals deserve to have access to affordable and adequate healthcare coverage. Currently, Utah's application does not and will not meet this standard. Thank you for the opportunity to provide comments. Please feel free to reach out to me at cgreenblatt@ghlf.org if you have any questions.

Respectfully submitted,



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Global Healthy Living Foundation

³ Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018. Available at <https://www.rollcall.com/news/politics/medicaid-kentucky>.

⁴ Renuka Tipirneni, Susan D. Goold, John Z. Ayanian. Employment Status and Health Characteristics of Adults With Expanded Medicaid Coverage in Michigan. *JAMA Intern Med*. Published online December 11, 2017. doi:10.1001/jamainternmed.2017.7055

⁵ Ohio Department of Medicaid, 2018 Ohio Medicaid Group VII Assessment: Follow-Up to the 2016 Ohio Medicaid Group VIII Assessment, August 2018. Accessed at: <http://medicaid.ohio.gov/Portals/0/Resources/Reports/Annual/Group-VIII-Final-Report.pdf>

